

# Practice Group

## Overall System for Deaf/HH Children Birth-5

System Goals:

### I. Identification

- a. To identify Deaf/HH children ages 0-5 as early as possible.
- b. To provide a single point of entry and easy transition from screening to diagnostic audiology.

System Elements:

#### a. Newborn Hearing Screening

1) Are there problems/issues that are prohibiting us from reaching our vision and goals?

- Pediatricians/Family Practice needs additional training.
- Hospitals screeners need to be better trained.
- Doctors also need to be more supportive around comprehensive screening.
- Hospital screening needs to be more comprehensive to rule out additional health issues.
- Need to connect children born under midwives.
- Chance of parents going to health departments—newborns born at home are rare.
- Can Health Department call parents of home births to offer screening?
- Need appointments set prior to leaving hospitals.

2)What needs to happen to put this in place?

- Screeners need better training and not to diagnose at screening.
- Screeners need to discontinue multiple screenings, but to refer out.

3)Who needs to be involved? What agencies/programs need to be involved?

#### b. Transition to re-screen

1) Are there problems/issues that are prohibiting us from reaching our vision and goals?

- Lose parents between hospital discharge and follow-up.

2)What needs to happen to put this in place?

3)Who needs to be involved? What agencies/programs need to be involved?

#### c. Re-screen

1)Are there problems/issues that are prohibiting us from reaching our vision and goals?

2)What needs to happen to put this in place?

3)Who needs to be involved? What agencies/programs need to be involved?

#### d. Transition from re-screen to diagnostic evaluation

1)Are there problems/issues that are prohibiting us from reaching our vision and goals?

2)What needs to happen to put this in place?

3)Who needs to be involved? What agencies/programs need to be involved?

- Project/Child Find Coordinator
- Early On Providers
- Parents and people who are deaf to work with the children and families.
  - Use technology to expand the system's capacity
  - Website access to communicate with parents
  - School for the Deaf /Low Incidence Outreach (LIO)
  - A mentorship center like in Maine. Must address the strengths of the deaf-mentors.
  - A centralized agency
  - Video Conferencing; but better with a live person. This helps to demonstrate how various methods work.

#### **e. Diagnostic Evaluation**

1)Are there problems/issues that are prohibiting us from reaching our vision and goals?

- There needs to be support right when parents find out that child may have hearing loss.
- System of support needs to acknowledge that child with hearing loss is child first and needs to be loved. Should not focus on medical issues only, focus on whole child.
- How do you include social and language issues via medical community?
- Parents do not get all information; big push on cochlear implant. All information given to parents can be overwhelming at first. Information should be shared at right moments.
- Doctors can not give all the information/support. Need to connect as early as possible to other resources. Guide By Your Side/Early On (e.g.)
- Medical community there for medical issues. Need different resources to learn about other resources.
- Who is paying for what? Information needs to be accurate and shared with everyone.
- Some companies do not charge for hearing test. School district that does not have audiologist will reimburse for cost of hearing test.

2)What needs to happen to put this in place?

3)Who needs to be involved? What agencies/programs need to be involved?

#### **f. Referral/Transition to Service Coordination**

1) Are there problems/issues that are prohibiting us from reaching our vision and goals?

- Need to have medical community work with Deaf Community to improve support.

2)What needs to happen to put this in place?

3)Who needs to be involved? What agencies/programs need to be involved?

- We need a “cookbook” approach on how to help families.

- Make sure everyone has the 1-800-EarlyOn number.

**g. Periodic hearing screening throughout childhood**

- i. Monitoring risk factors for progressive/late onset hearing loss

1) Are there problems/issues that are prohibiting us from reaching our vision and goals?

- Elimination of school-age screening funding for young children? Governor has recommended that it is fully restored. Final word to come June/July.
- Kindergartener screened and informed to get an audiogram on their own expense.
- Early On has instruments for hearing and vision screening.

2) What needs to happen to put this in place?

3) Who needs to be involved? What agencies/programs need to be involved?

**h. Awareness**

- i. Public
- ii. Parents
- iii. Professionals

1) Are there problems/issues that are prohibiting us from reaching our vision and goals?

2) What needs to happen to put this in place?

3) Who needs to be involved? What agencies/programs need to be involved?

- Public Awareness/Public Relations via Health Department and Early On/Individuals with Disabilities Ed Act, Community Mental Health, Head Start, providers of preschool, training sites for medical personnel/providers (Higher Education)
- Using outreach workers to spread the word.

**i. Data file begins with EHDI**

1) Are there problems/issues that are prohibiting us from reaching our vision and goals?

- Spectrum has a patient care coordinator to follow-up on families to get them back for screening. Hospitals could provide this support.

2) What needs to happen to put this in place?

3) Who needs to be involved? What agencies/programs need to be involved?

**j. Procedural Safeguards/Family Rights**

1) Are there problems/issues that are prohibiting us from reaching our vision and goals?

- Parents need to have their rights explained. Not sure if parents receive rights while in hospitals.

2) What needs to happen to put this in place?

- To address this issue, need a knowledgeable, unbiased person to explain to families. Need to put policy in place to cover the rights.

3) Who needs to be involved? What agencies/programs need to be involved?

**k. Mandatory Reporting**

1)Are there problems/issues that are prohibiting us from reaching our vision and goals?

- There is a new law. The information required is very specific and it is not always clear what to do.
- Physicians with the equipment in their office may not know what to do either. (Need policy and rules to help with the implementation of the new law)

2)What needs to happen to put this in place?

- EHDI needs to do a campaign regarding the new law.

3)Who needs to be involved? What agencies/programs need to be involved?

- Michigan State Medical Society needs to do a bulletin. (EHDI needs to work with the Society) also et al involved with children with hearing loss. (CSHCS, Early On, Audiologists, Equipment manufacturers, etc.)

## II. Service or Care Coordination

- a. To provide a seamless system of service delivery.
- b. Family access to key individuals at the beginning of identification to ensure uniform information provision.
- c. To provide a coordination of resources across agencies.

### System Elements:

- a. Coordinate communication between agencies
- b. Provide parents unbiased information on services.
- c. Access to unbiased information about communication options
- d. Review Eligibility determinations across agencies and funding issues
- e. Help to navigate transitions
- f. Links to appropriate services and qualified service providers
- g. Procedural Safeguards/Family Rights
- h. Single point of entry into system

### a. Coordinate Communication between agencies

1) Are there problems/issues that are prohibiting us from reaching our vision and goals?

2) What needs to happen to put this in place?

3) Who needs to be involved? What agencies/programs need to be involved?

- Early On should share with providers where to go for certain supports. The flow chart should be clear.
- Saginaw has a CSHCS/Early On nurse to facilitate support.
- Parents need to receive information from someone who is a trained expert.
- Need to have medical documents to help everything happen down the process.
- Colorado has a team approach to help family at the start. (various professionals that includes a expert familial support person should be involved)
- Early On does have a role to help families to navigate the system

### b. Provide Parents Unbiased Information

1) Are there problems/issues that are prohibiting us from reaching our vision and goals?

- Not a specific designated job of one entity.
- Geography limits resources.

2) What needs to happen to put this in place?

- Need a central source
- Need to not overwhelm family
- Point person from Early On or other source? An option of Guide by Your Side offered to families as well
- Need not be dependent of “people”
- Central source needed due to limited resources in each ISD
- Family training and professional training
- Universities need to train on low incidence outreach

3) Who needs to be involved? What agencies/programs need to be involved?

- Early On
- Michigan Department of Education
- Representatives of various options available
- Guide by your side offered to parents
- Designated specialists

**c. Access to unbiased information about communication options**

1) Are there problems/issues that are prohibiting us from reaching our vision and goals?

2) What needs to happen to put this in place?

3) Who needs to be involved? What agencies/programs need to be involved?

- Websites/other electronic resources
- Resource that could provide unbiased info
- List of individuals willing to answer questions
- National resources

**d. Review Eligibility determinations across agencies and funding issues**

1) Are there problems/issues that are prohibiting us from reaching our vision and goals?

- Varying eligibilities/resources and it is not clear who is eligible.
- Who is eligible for what?

2) What needs to happen to put this in place?

- Central resource person knowledgeable about eligibility requirements
- Hearing Aid Center/Loaner Program

3) Who needs to be involved? What agencies/programs need to be involved?

- Lions and other community organizations

**e. Help to navigate transitions**

1) Are there problems/issues that are prohibiting us from reaching our vision and goals?

- Lack of resources to help parents make decisions
- Families get lost in between steps
- No special education support for 3-5 year olds?
- Michigan School for the Deaf is not widely known by parents
- Need parent support system in general
- Special education parents list
- Hospitals need to re-screen those that fail newborn hearing screening
- Doctors need to follow through and understand their role

2) What needs to happen to put this in place?

- Parents need to receive training on their rights and entitlements
- Various support models are needed throughout state
- Organization not connected to government to provide support
- All resources should be placed on the Low-Incidence Outreach website/EHDI website/others

3) Who needs to be involved? What agencies/programs need to be involved?

- Michigan Department of Education
- Michigan Department of Community Health (MDCH)—Early Hearing Detection and Intervention Program
- MDCH-Guide by Your Side Program
- Hands and Voices

#### **f. Links to appropriate services and qualified service providers**

##### **1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

- Lack of experts on the various options

##### **2) What needs to happen to put this in place?**

- Outreach
- Central source
- Regional approach
- Use technology to distribute info
- Video/distance technology
- Use the Colorado/Ski-Hi models/regions for resources

##### **3) Who needs to be involved? What agencies/programs need to be involved?**

- Michigan Department of Education
- Various Experts

#### **g. Procedural Safeguards/Family Rights**

##### **1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

- No one really understands the needs of young children with hearing loss and their family needs in Michigan to help parents with a deaf child.
- Procedural Safeguards are not specific to families who are struggling with hearing loss
- Need to have various resources to address different learning styles
- No liaisons for families to help with advocacy
- Need to incorporate developmental milestones
- Service Coordinators need to be knowledgeable regarding procedural safeguards

##### **2) What needs to happen to put this in place?**

- Train the trainer for parents
- Connect with MAASE to educate administrators to make them current
- The Parent Leadership entity needs to be there to help families work with schools

##### **3) Who needs to be involved? What agencies/programs need to be involved?**

#### **h. Single point of entry into system**

##### **1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

- No central point for parents to contact and it is accessible to parents
- Flowchart for support
- Resource packet
- Need to share EHDI resource guide

2)What needs to happen to put this in place?

3)Who needs to be involved? What agencies/programs need to be involved?



### III. Eligibility Determination

- a. To determine eligibility in a timely manner.

#### System Elements:

- a. CSHCS
- b. Medicaid
- c. MICHILD
- d. Private insurances
- e. Early On
- f. Special Education
- g. Healthy Kids
- h. SSI
- i. Procedural Safeguards/Family Rights

#### 1) Are there problems/issues that are prohibiting us from reaching our vision and goals?

- Issue around delivery in timely manner (CSHCS)
- Parents could use help on coverage of services (Private Insurance)
- Lack of providers to make it timely
- Speech/language services are reimbursed at a low rate (CSHCS)
- More families need to know about MICHILD
- Need to know which resources will pay for which services
- Turf-ism

#### 2) What needs to happen to put this in place?

- Pass law to use private insurance to pay for early intervention services
- Need to target providers to help streamline process (CSHCS)
- Central eligibility process
- Guide families through the processes when interested

#### 3) Who needs to be involved? What agencies/programs need to be involved?

- Regional Centers
- CSHCS/Medicaid (Cover mostly the same)
- Michigan Department of Education

## IV. Plan Development

- a. Family and child-centered services which identify and respect the family choices.
- b. To provide a choice of services that is specific to the needs, capabilities, and decisions of the child and family.

### System Elements:

- a. Needs/Service Assessment
- b. Gather information on child's needs and development.
- c. Families concerns, priorities, and resources.
- d. The full range of services that will be utilized by the child and family.
- e. Develop language/communication plan.
- f. Procedural Safeguards/Family Rights

#### a. Needs/Service Assessment

1) Are there problems/issues that are prohibiting us from reaching our vision and goals?

2) What needs to happen to put this in place?

3) Who needs to be involved? What agencies/programs need to be involved?

- Need to identify and support children eligible for 504
- Need adequate personnel
- Need for and better use of instruments to assess sign skills for infants/toddlers (e.g. SKI-HI tool)

#### b and c (gather information and concerns, priorities, and resources)

1) Are there problems/issues that are prohibiting us from reaching our vision and goals?

- Lack of knowledge on how to work with all families (e.g. transient families)
- Lack of uniform process
- Look at form with various support domains (universal plan of service form)

2) What needs to happen to put this in place?

- Need a form that meshes medical, educational, language, and family needs
- Special education staff need training on IFSP
- Train parents on IFSP/IEP components, family rights and process (with focus on deaf and H/H children)

3) Who needs to be involved? What agencies/programs need to be involved?

- Part C
- Special Education

#### d. The full range of services that will be utilized by the child and family

1) Are there problems/issues that are prohibiting us from reaching our vision and goals?

- Services not equally distributed
- Not all people have access to all services
- Parents don't know that districts can pay for service delivered by other resource that the district does not have

- At times, districts request multiple diagnoses unnecessarily
- Some IEP teams do not have access to specialist in hearing loss
- No hotline to get info on law
- Need more information on the 504 law

2)What needs to happen to put this in place?

- Regional Centers
- Better use of 504 law

3)Who needs to be involved? What agencies/programs need to be involved?

**e. Develop language/communication plan**

1)Are there problems/issues that are prohibiting us from reaching our vision and goals?

- Appropriate tools needed
- Inadequate access to speech/language support
- Inadequate number of personnel
- Low expectations for the children with hearing loss

2)What needs to happen to put this in place?

- Pre-service/in-service preparation needs to be updated and kept current
- Goal training for parents/professionals working with children with hearing loss
- Special education personnel should rotate in general education to keep abreast of typical development

3)Who needs to be involved? What agencies/programs need to be involved?

## V. Services

- a. To provide access to high quality services so that the family and child will reach their full potential.
- b. Qualified pediatric service providers.

### System Elements:

#### Formal Services

##### a. Audiology

#### 1) Are there problems/issues that are prohibiting us from reaching our vision and goals?

- Difficulty in getting good diagnoses by pediatric providers
- Lack of pediatric providers
- Difficulty for providers to stay current in pediatric skills
- Parents need to be prepared to make multiple visits

#### 2) What needs to happen to put this in place?

- Licensure requirements to maintain skills

#### 3) Who needs to be involved? What agencies/programs need to be involved?

##### b. Speech-Language Pathology

#### 1) Are there problems/issues that are prohibiting us from reaching our vision and goals?

- Speech/Lang Path not all are trained in pediatric skill
- More is not always better
- Need more S/P with sign skills
- Improve ability to diagnoses co-existing problems

#### 2) What needs to happen to put this in place?

- Sound Support kinds of services
- Increase in personnel for hearing impaired

#### 3) Who needs to be involved? What agencies/programs need to be involved?

##### c. Consultants

- i. Hearing Impaired
- ii. Teacher Consultant

#### 1) Are there problems/issues that are prohibiting us from reaching our vision and goals?

- (note: some participants do not like the term hearing impaired)
- Do not know the difference between HI and TC
- HI consultants can rarely sign
- TC consultants need to sign
- Should TC consultants be stricken? Need to be considered

#### 2) What needs to happen to put this in place?

- A special education rule change

#### 3) Who needs to be involved? What agencies/programs need to be involved?

**d. (1) Sign Instructors/Interpreters (should be separated)**

**1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

- Foreign language should include ASL
- Interpreters should be qualified with appropriate credentials

**2) What needs to happen to put this in place?**

- Licensure/certification

**3) Who needs to be involved? What agencies/programs need to be involved?**

- Division on Deafness and Hard of Hearing
- Low Incidence Outreach

**e. Medical Home/PCP**

- i. Communication with the medical home
- ii. Medical home identified as the primary care physician

**1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

**2) What needs to happen to put this in place?**

**3) Who needs to be involved? What agencies/programs need to be involved?**

- Doctors need more training/guidance
- Improve reporting by primary care physician

**f. Specialty referrals for children identified with hearing loss to otolaryngology, genetics, ophthalmology, and others as needed**

**g. Assistive Technology**

**h. Teacher/Early Interventionist**

**j. Other**

**i. Counseling**

**ii. Social worker**

**1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

**2) What needs to happen to put this in place?**

**3) Who needs to be involved? What agencies/programs need to be involved?**

- Professionals need to understand the behavioral issues involved
  - Need to provide training/resource list who are experts in working with Deaf/HH
- Provide and access resources

**Informal Services**

- a. Role Model/Mentors
- b. Parent-to-Parent Support
- c. Support Groups
- d. Support Organizations

**1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

- Parents need mentors to provide support
- (SKI HI has a deaf mentorship program)

## 2)What needs to happen to put this in place?

- Shared Reading Project: resource person visits home to demonstrate how to read book to child (Bloomfield and MSD)
- Books on tape that signs story
- Adult role model who is deaf to do reading

## 3)Who needs to be involved? What agencies/programs need to be involved?

- Self Help newsletters
- Educational Audiologists Journal Association

## **VI. Quality Assurance/System Evaluation/Accountability**

- a. Monitoring of outcomes serves as a basis for service planning and review
- a. Integrated data system
- b. Establishment of joint system outcomes
- c. Joint/Aligned Policy

### **System Elements:**

- a. Evidence-based joint system outcomes
- b. Monitoring of outcomes serves as a basis for service planning
- c. Evidence- based monitoring of progress
- d. Monitor, review child's progress over time
- e. Implement IFSP, monitor, review and conduct six month review
- f. Procedural Safeguards/Family Rights
- g. "Specialization" of service providers
- h. IEP birth to 5
- i. Tracking database for outcome measures

1)Are there problems/issues that are prohibiting us from reaching our vision and goals?

- Shared-info system lacking

2)What needs to happen to put this in place?

3)Who needs to be involved? What agencies/programs need to be involved?

### **Regional Centers/Services**

- Individual(s) supported with appropriate resources to support families. (similar to Colorado)
- Central source for resources
- Uses video link to enhance access
- Lack of qualified providers begs use of technology to increase access
- One single point of entry: a) Low Incidence Outreach; b) EHDI; c) charitable organizations (Sertoma, Holley Ear Inst, Lions, Carl, Deaf Can, MADHH); d) MSD

### **Regional Issues/Boundaries**

- UP
- Detroit/Metro Area
- Large Hospitals (UM, Munson, Marquette, etc)
- Diagnostic Centers
- Educational regions (See Anita at Sound Support for identification of resources)
- Also contact for informal supports
- Who will oversee? – EHDI/Special Education
- Shared Reading Project, SKI-HI
- Care Coordination/Ed specialists